



***NHS to LHS:
How can big data transform the National Health
Service into a learning health system?***

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25th October 2019



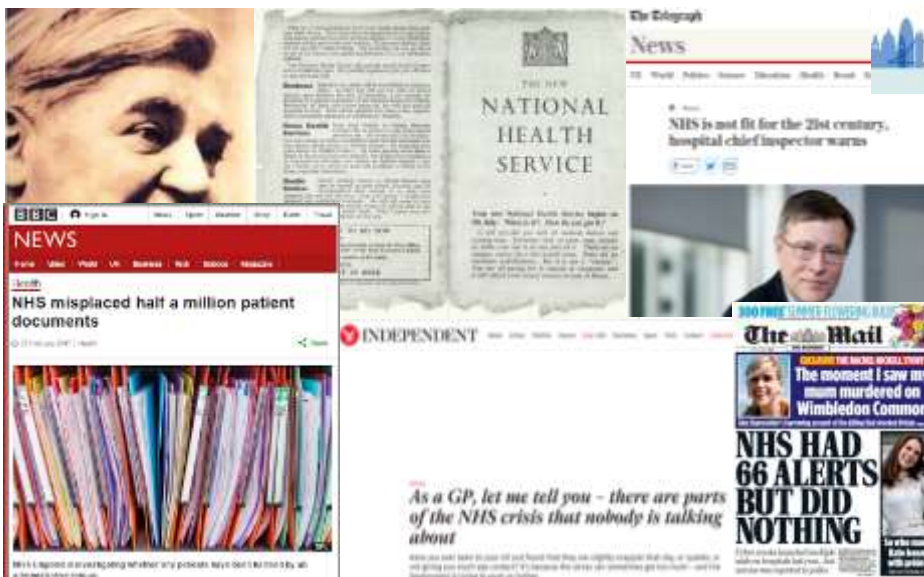
Conflicts of interest

- 30% clinical, 70% academic
- Advisory boards: Novo Nordisk, Boehringer-Ingelheim, Pfizer, Astra-Zeneca
- Research funding: Innovative Medicines Initiative, European Research Council, NIHR, HEFC, British Heart Foundation, BMA Research Foundation
- Trustee, South Asian Health Foundation
- Research interests: digital health, EBM, informatics, medical education





THE MESS





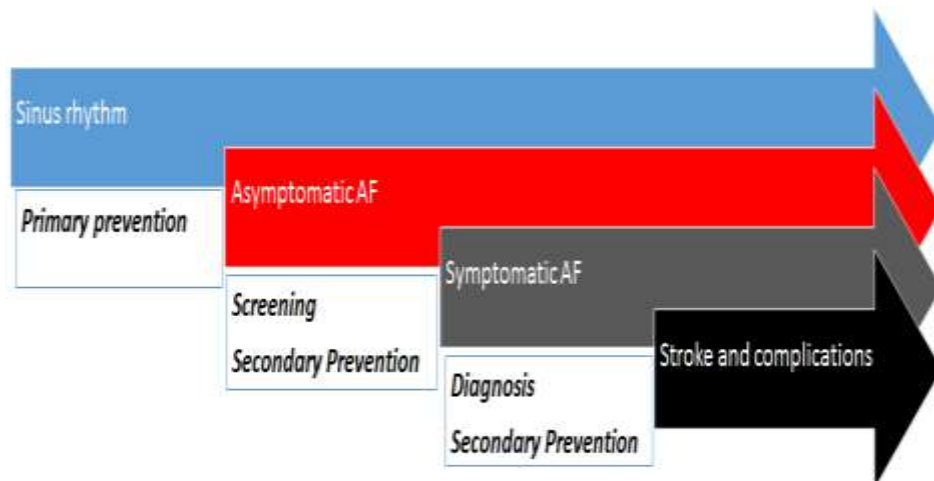
Save our NHS



At the bedside

- 60 year old man
- Palpitations
- AF





Reality at the bedside

- No personalised tools for predicting risk of AF
- New drugs, but which one?
- No notes from GP/patient/hospital

Cascade of waste



Science: What causes AF? What are the risk factors?

Evidence: New drugs, but which one?

Care: No notes from GP/patient/hospital

Neglecting any of these three factors can be detrimental to individuals and patients





PEOPLE WHO LIKE TO DRAW CYCLES

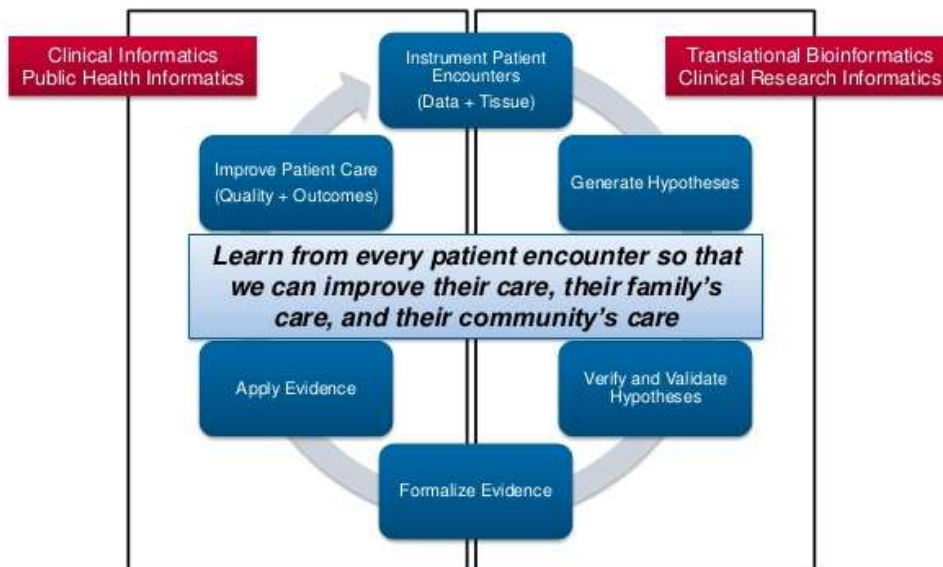


Continuously learning healthcare system





The scope of LHS



Learning Health Systems

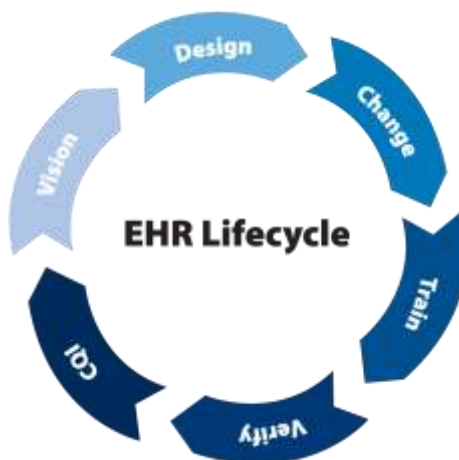




Not this

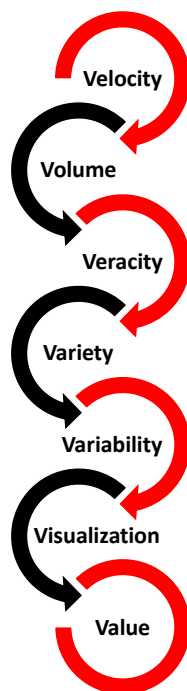
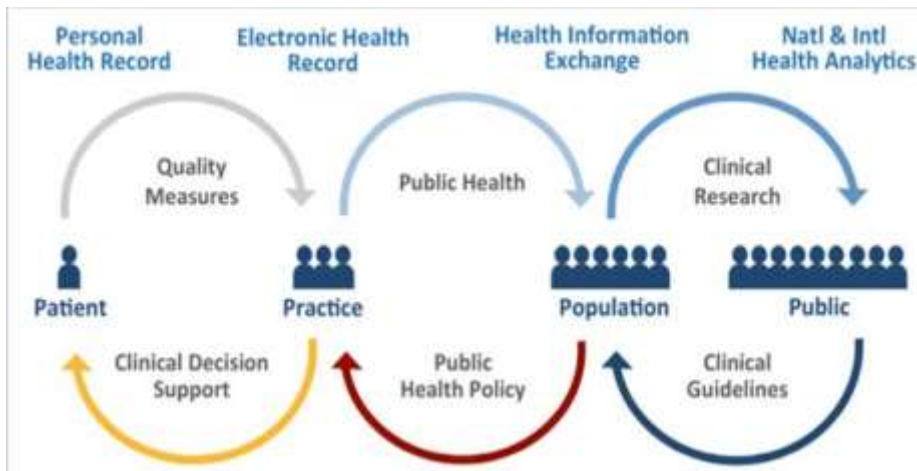


EHR



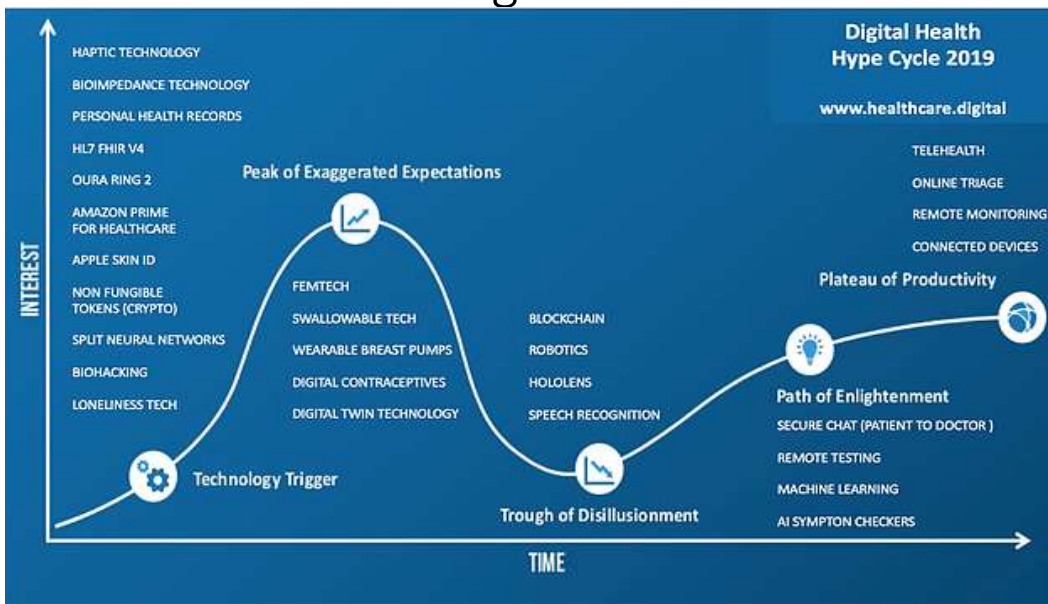


IT and learning health systems





Big Data is Out



Patient-centred healthcare



The gap between promise and reality

Conclusions

This review identified some benefits in the quality of care but did not provide evidence that the implementation of eHealth interventions had a measurable impact on cost-effectiveness in hospital settings. However, further evidence is needed to infer the impact of standards adoption or interoperability in cost benefits of health care; this in turn requires further research.

Conclusions: PROMs data act as 'tin openers' rather than 'dials'. Providers need more support and guidance on how to collect their own internal data, how to rule out alternative explanations for their outlier status and how to explore the possible causes of their outlier status. There is also tension between PROMs as a QI strategy versus their use in the care of individual patients; PROMs that clinicians find useful in assessing patients, such as individualised measures, are not useful as indicators of service quality.

Conclusion: For every hour physicians provide direct clinical face time to patients, nearly 2 additional hours is spent on EHR and desk work within the clinic day. Outside office hours, physicians spend another 1 to 2 hours of personal time each night doing additional computer and other clerical work.

CLEANING THE MESS



- Analysis of risk factors
- Improve disease definition
- Risk prediction models
- Inform future discovery science and trials
- Understanding of disease mechanism and drug targets



- Automation/machine learning built into EHR for evidence/guidelines
- Real world EHR trials
- Comparative effectiveness research
- Surveillance
- Personalised recommendation



- Prospective not retrospective
- Decision support
- Real-time linkage
- Interoperability
- Include patient experience, wearable and –omic data
- Patient can see and use their own data



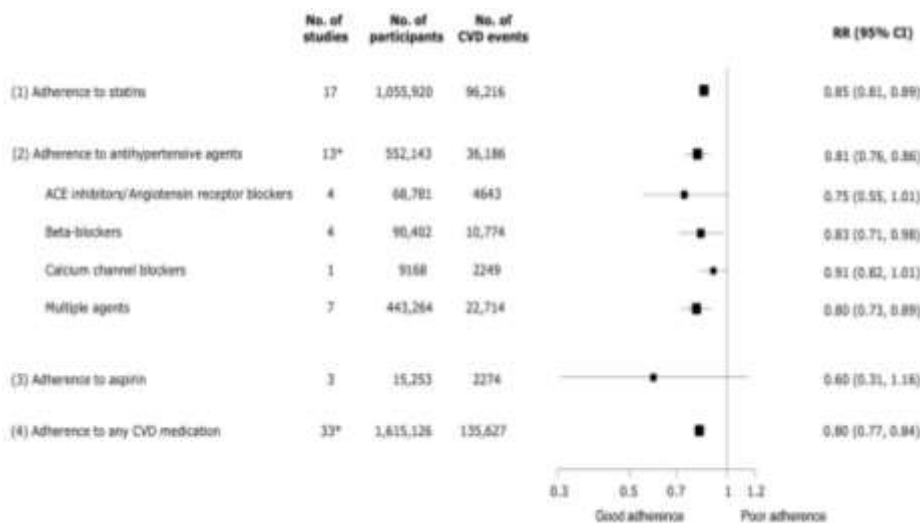


Reviews emphasising IT and research

- Francis 2013
- Keogh 2013
- Wachter 2016
- Caldicott 2017
- Topol 2018
- We don't need more reviews and reports



Adherence and CVD events

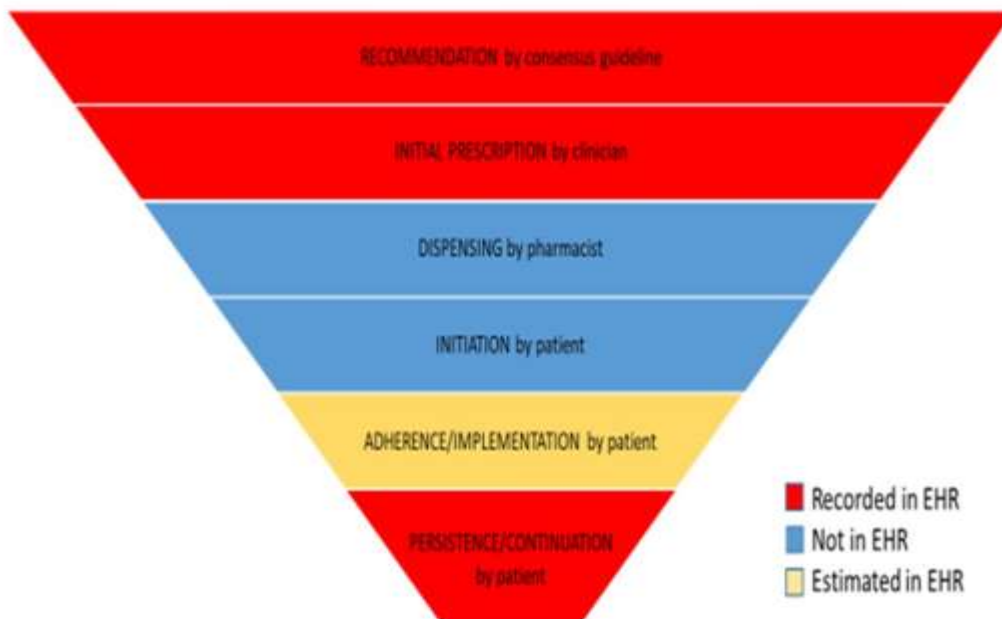
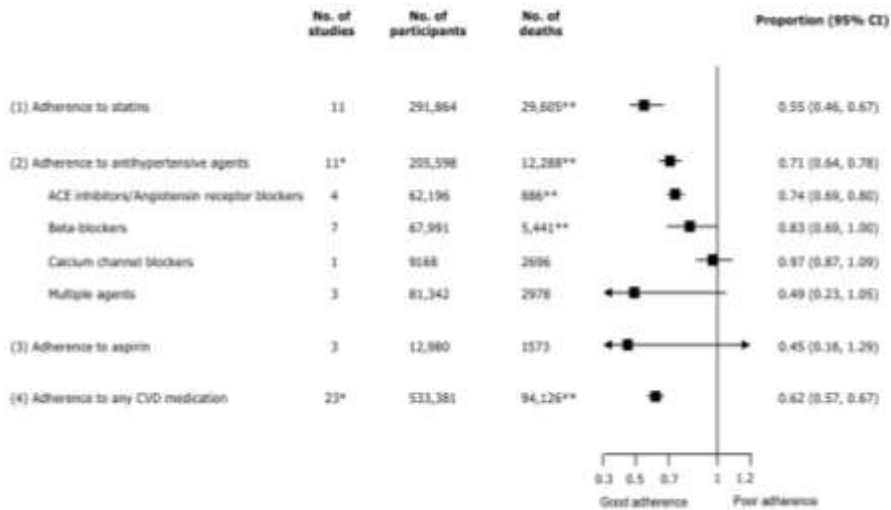


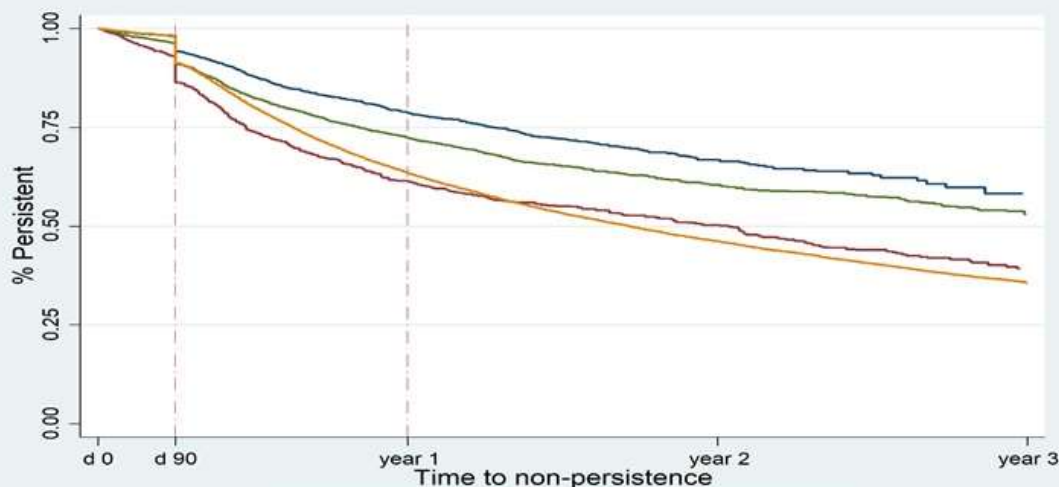
Chowdhury et al. *EHI*. 2013.





Adherence and deaths





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Value (1)



	<p>2008</p> <p>HF</p> <ul style="list-style-type: none"> • Systolic • Diastolic 	<p>2012</p> <ul style="list-style-type: none"> • HFrEF (LVEF<35%) • HFpEF (LVEF>50%) <p>structural heart disease, diastolic dysfunction</p>	<p>2016</p> <ul style="list-style-type: none"> • HFrEF (LVEF<40%) • HFmrEF (LVEF 40-49%) • HFpEF (LVEF≥50%) <p>BNP, structural heart disease, diastolic dysfunction</p>
	<p>2006</p> <p>AF</p> <ul style="list-style-type: none"> • First detected • Paroxysmal (self-terminating) • Persistent (non self-terminating) • Permanent 	<p>2010</p> <ul style="list-style-type: none"> • Paroxysmal (usually≤48 hrs) • Persistent (>7 days or requires CV) • Long-standing Persistent (>1 yr) • Permanent 	<p>2016</p> <ul style="list-style-type: none"> • AF secondary to structural heart disease • Focal AF • Polygenic AF • Post-operative AF • AF in patients with mitral stenosis or prosthetic heart valves • AF in athletes • Monogenic AF



Value (2)

- Human and machine readable
- Validated
- Stakeholder acceptability
- Multiple phenotypes (e.g. 8 for AF)
- Multiple data types
 - Hospital and primary care EHR
 - Trial data
 - Registry data
- Multiple countries



Value (3)

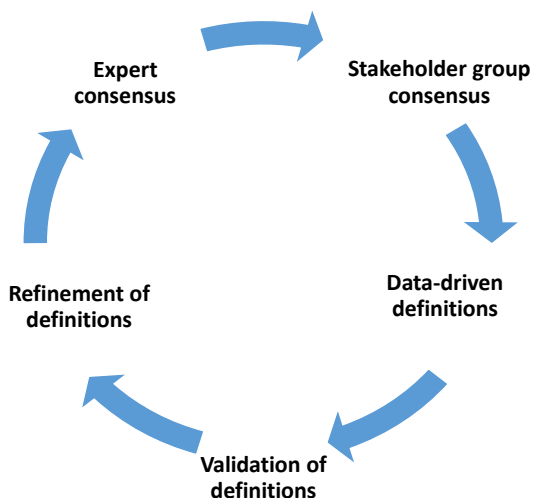
The screenshot shows a web browser displaying a clinical review article. The browser address bar shows the URL: <https://www.heartjnl.com>. The page header includes the ESC logo, the journal title "European Heart Journal (2018) 39, 1481–1495", and the article type "CLINICAL REVIEW". The main content area features the "BigData@Heart" logo and the tagline "Big Data For Better Hearts". A navigation menu is visible with links for Home, About, Partners, News, Newsletter, Webinars, Publications, Contact, and Member Area. The main image is a close-up of a red rope knot on a wooden branch. At the bottom, there is a "News" section with the headline "Big Data For Better Outcomes: NHS selected" and a date "Posted on July 05, 2018 14:28". A footer note states: "Received 1 June 2017; revised 19 July 2017; editorial decision 2 August 2017; accepted 8 August 2017; online publication of article 18 August 2017".





Value (4)

WP2: Disease understanding and outcomes definition



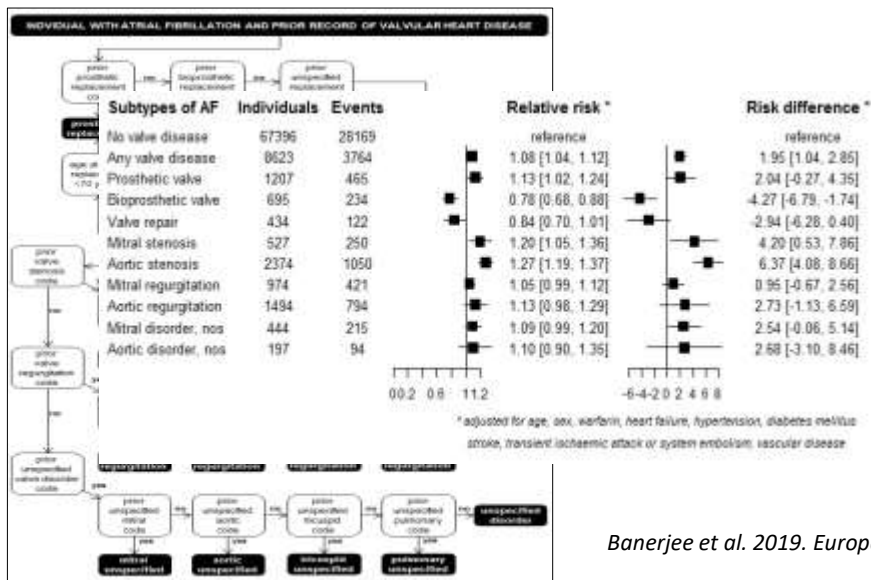
Value (5)



AF type	EHR phenotype description	ICD 10	Read	OPCS 4	BNF	Refs.
AF secondary to structural heart disease	<ul style="list-style-type: none"> LV systolic/diastolic dysfunction, and/or heart failure Long-standing hypertension with LV hypertrophy Congenital heart malformations Cardiomyopathies Valvular heart diseases Other structural heart disease 	✓	✓	✓	✓	1-4
Focal AF	<ul style="list-style-type: none"> Paroxysmal AF Symptomatic AF Atrial ectopy and/ or atrial tachycardia 	✓	✓			1
Polygenic AF	<ul style="list-style-type: none"> Inferred: very early onset AF not elsewhere classified 					1,5
Post-operative AF	<ul style="list-style-type: none"> Open / closed cardiac surgery Other/ any surgery 			✓		1,6,7
AF with mitral stenosis/ prosthetic valves	<ul style="list-style-type: none"> Mitral stenosis Prosthetic heart valves 	✓	✓	✓		1,8
AF in athletes	<ul style="list-style-type: none"> Professional, or high level sports participation Inferred: Other sports occupations e.g. sports coaches could infer former athletes 		✓			1
Monogenic AF	<ul style="list-style-type: none"> Long-QT, Brugada, Wolff-Parkinson-White syndrome 	✓	✓			1,4
AF secondary to respiratory disease *	<ul style="list-style-type: none"> COPD Sleep apnoea Pulmonary hypertension 	✓	✓			1,9



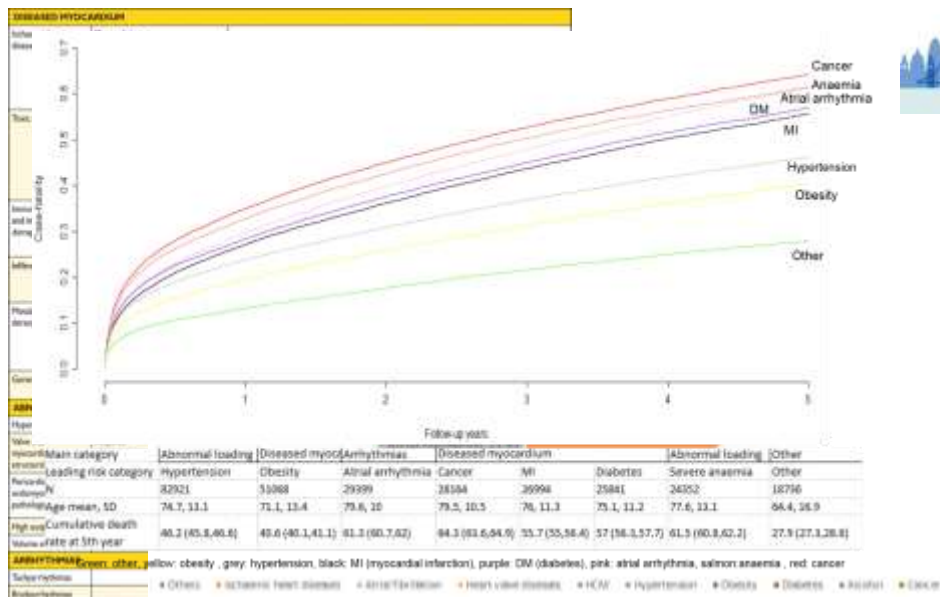
Value (6)



Banerjee et al. 2019. Europace



Value (7)





Value (8)

1. Interoperability

- Across study designs
- Across clinical settings
- Across universities and hospitals
- Across countries

2. Agreement of coding and definitions

3. Improved quality and use of routine clinical data

4. Potential EHR trials



HEALTHCARE

VITAL DIRECTIONS FROM THE NATIONAL ACADEMY OF MEDICINE

Health Information Technology Interoperability and Use for Better Care and Evidence

Executive Panel:
MELINDA PERIN,
Hospital Corporation of
America, Executive
Director

Editorial Support:
KATHY
AND NICK

The past decade has seen an explosive growth in health information technology (HIT) as a mechanism for improving efficiency and quality, gaining more accountability and reducing purchasing, advancing the role and engagement of consumers in their own health decisions, accelerating discovery and dissemination of new treatments and therapies, and changing public health monitoring and surveillance. Supported by federal incentives through the Health Information Technology for Economic and Clinical Health Act, information technology and electronic health records (EHR) have been implemented in nearly all hospitals and the majority of physician practices, as well as other sites of care. Electronic health records and other points of care information tools for clinicians have become an essential component of health care operations.

Despite this progress, other goals for HIT have not been realized. Persistent efforts to connect and aggregate health information so it follows patients through care have been limited by financial concerns, inconsistent interoperability standards, and incomplete specification of end-to-end standards. Progress against the information they need to help manage their own care has likewise advanced through goals and other access tools, but is limited due to a lack of accessibility, functionality, and interoperability. Data intensive activities, such as research and public health surveillance, have not been enabled to leverage the already collected electronic health information.

As HIT matures, it will bring some substantial changes to health care even in the absence of further government action. Adoption of HIT by consumers, academic practices as health care, and rapidly changing HIT will drive these changes. Policy makers should take their attention to the interoperability and sharing of health information through health care stakeholders, which is central to realizing the economic and clinical benefits of HITs and also celebrate making the health care marketplace more efficient. One estimate suggests that HIT will realize the goal of a substantial reduction in

inequity, expensive, high quality, and cost-effective health care. The following themes and policy recommendations are priority considerations as the future of HIT evolves.

Data Standards and Achieving Interoperability at Scale
To support the sharing of data, data standards and the supporting infrastructure, policies, and incentives that facilitate end-to-end interoperability of patient health data across providers, IT products, and data generating medical technologies need to be created. Future federal programs should focus on making infrastructure, training, and strengthening heterogeneous policies to reduce barriers and promote the exchange of data.

Interoperability With Consumer HIT
Patient costs and responsibility for care are being shared for access to personal (and family) health information, including integrating patient-generated health data from alternative sources of care and consumer health products. Patients and health care organizations will need to provide interoperability and maintain data integrity while not favoring innovation.

Improving Patient Identification and Data Matching
Errors in patient data matching can result in suboptimal care and medical errors. Congress should continue its efforts to advance accurate patient identification by addressing the adoption of common demographic fields and data elements.

Architecture and Web-Based Services
Realizing the best return on the substantial investment already made by the federal government and health care organizations in EHRs requires opening up APIs to vendors, web-based software applications, local networks, and mobile devices through application programming interfaces that support a dynamic and non-proprietary information infrastructure. This is true for various research methods in the network for



-Commit to end-to-end interoperability extending from devices to EHR systems.

-Aggressively address cyber security vulnerability.

-Develop a data strategy that supports a learning health system.



Science

• HDR-UK



Undergraduate medical training in HI





Postgraduate training in HI



Open access Research

BMJ Open Health informatics competencies in postgraduate medical education and training in the UK: a mixed methods study

Lydia Jidkov,¹ Matthew Alexander,² Pippa Bark,¹ John G Williams,^{3,4} Jonathan Kay,⁵ Paul Taylor,¹ Harry Hemingway,^{6,7} Amitava Banerjee^{8,1,4}

To cite: Jidkov L, Alexander M, Bark P, et al. Health informatics competencies in postgraduate medical education and training in the UK: a mixed methods study. *BMJ Open* 2019;9:e025460. doi:10.1136/bmjopen-2018-025460

• Preparation factors and additional material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2018-025460>).

ABSTRACT
Objective To assess health informatics (HI) training in UK postgraduate medical education, across all specialties, against international standards in the context of UK digital health initiatives (eg, Health Data Research UK, National Health Service Digital Academy and Global Digital Exemplar).
Design A mixed methods study of UK postgraduate clinician training curricula (71 specialties) against international HI standards: scoping review, curricula content analysis and expert consultation.
Setting and participants A scoping literature review (PubMed until March 2017) informed development of a contemporary framework of HI competencies, domains for

Strengths and limitations of this study

- In the first comprehensive study across all 71 specialties in UK postgraduate medical training, we showed that health informatics (HI) is grossly under-represented in postgraduate clinical training curricula.
- A mixed methods design (scoping literature review, curricula content analysis and expert consultation) allowed iterative development of a contemporary, generalisable HI competency framework for all doctors.
- A possible limitation was the subjective nature of

Consultant General Practitioner (GP)



Undergraduate training in HI



Tweet

Amit Banerjee
@amibanerjee1

Great to launch our new module, "Doctor as Data Scientist" to all our 1st year MBBS students @UCLMS today. @doctordeborah

Doctor as Data Scientist

New course, new territory, new aims

- skills to access, understand and evaluate research evidence for clinical decision making
- digital health
- data-driven technology in healthcare
- learning health systems- science, evidence and care

11:45 AM · Oct 9, 2019 · Twitter for Android



Postgraduate training in HI



Digital Cardiology

A British Cardiovascular Society National Symposium

British Cardiovascular Society, London, 1st November 2019

08:30 – 09:00	Registration	
09:00 – 09:10	Welcome and introduction to digital cardiology	Dr Arifava Banerjee Dr Shouvik Halder
Session 1 Artificial Intelligence in Cardiology		
09:10 – 09:30	Use of artificial intelligence in cardiology	Professor Steffen Petersen
09:30 – 09:50	Systematic review of clustering and prediction in CVD	Dr Arifava Banerjee
09:50 – 10:10	Machine learning in cardiovascular risk prediction-ready for prime time?	Professor Mihalis van der Schuer
10:10 – 10:40	Panel discussion – Open to Floor Artificial intelligence – How do we use it in cardiology?	Chair: Professor Steffen Petersen



Evidence

- Digital Academy
- Faculty of Clinical Informatics (FCI)
- Federation of Informatics Professionals (Fed-IP)



NHS England

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News

Top universities will host new Academy to train digital healthcare leaders of the future

3 August 2017
Digital Innovation

Three of the world's top universities will provide virtual masterclasses in leadership and digital as part of a comprehensive programme to provide NHS staff with the right skills to drive digital innovation.

The NHS Digital Academy, led by Imperial College London's Institute of Global Health Innovation in partnership with Harvard Medical School and The University of Edinburgh will train for world leaders in tomorrow.



- Global Digital Exemplar programme



Global Digital Exemplars: "Ivy League"



All commentary?



Big Data for cardiology: novel discovery?
Walter Pflieger-Schindler*

Abstract Big data, combined with emerging machine learning techniques, is expected to revolutionize the way we understand and manage cardiovascular disease. This article discusses the potential of big data in cardiology, the challenges of data integration and the need for a multidisciplinary approach to data analysis.

Keywords: Big Data • Machine Learning • Healthcare • Quality • Evidence • Digital Health

Big data analytics to improve cardiovascular care: promise and challenges
John A. Baxendale^{1,2}, Robert E. Vogel^{1,2} and Thomas A. Manolis^{1,2}

Abstract The potential for big data analytics to improve cardiovascular quality of care and patient outcomes is enormous. However, the application of big data in health care is a nascent stage and the evidence is often demonstrating that big data analytics will improve care.



All commentary?



SPECIAL ARTICLE

Big Data for cardiology: novel discovery?

Walter Pflieger-Schindlberger*

Abstract The potential of big data in medicine is widely recognized and discussed in the general public. However, it is not clear how big data can be used to improve patient care. This article discusses the potential of big data in cardiology and the challenges that need to be overcome to realize this potential.

Keywords: Big data • Healthcare • Cardiology • Quality • Evidence • Digital health

REVIEWS

Big data analytics to improve cardiovascular care: promise and challenges

John A. Baxendale^{1,2}, Daniel E. Joshi^{1,2} and Thomas Al. Mihalik^{1,2}

Abstract The potential for big data analysis to improve cardiovascular quality of care and patient outcomes is tremendous. However, the application of big data in health care is not...

DOI: 10.1136/bmjopen-2019-025000

BMJ Open 2019;13:e025000.

Are We Up to Speed?

From Big Data to Rich Insights in CV Imaging for a Hyperconnected World

Jagan Narula, MD, PhD

The first wireless implementation of the first image display was developed in 1991 (1) and has been used since then as a mainstay tool in cardiac imaging for understanding cardiovascular disease. However, the application of big data in health care has identified how data in a common form for selection



All commentary?



SPECIAL ARTICLE

Big Data for cardiology: novel discovery?

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REVIEWS

Data-driven healthcare: from patterns to actions

Al Daghraoui¹ and N Bano²

Abstract The potential for big data analysis to improve cardiovascular quality of care and patient outcomes is tremendous. However, the application of big data in health care is not...

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BMJ Open 2019;13:e025000.

Viewpoints

Harnessing the Heart of Big Data

Sarah B. Stranges, Karol Watson, Andrew I. Su, Henning Hermsjakob, John R. Yates III, Merry L. Lindsey, Peipei Ping

Are We Up to Speed?

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Outstanding problems

- Is {...} making healthcare more efficient?
- Is {...} making healthcare more effective?
- Is {...} reducing inequalities?
- Is {...} causing harm?
- Is {...} aligning research and care?
- Is {...} dealing with ethical and regulatory concerns?



Summary

- Define the mess
- Draw cycles
- Clean the mess





Patient-centred vs Researcher/Data/Tech-centred

SCIENCE TRANSLATIONAL MEDICINE | EDITORIAL

POLICY

The study is open: Participants are now recruiting investigators

Recent events inspire optimism that a new age is dawning, one in which lay people have an active role in advancing biomedical research and health care delivery. Two ongoing experiments will deeply involve the public in these endeavors: the U.S. Precision Medicine Initiative (PMI) and the National Patient-Centered Clinical Research Network (PCORnet). PCORnet has already launched 20 patient-powered research networks designed to be led and animated by people who have an affinity with one another because of either shared disease, geography, experience, or identity (1). When U.S. President Barack Obama announced the PMI, he stated emphatically that people would be, not patients or even participants, but rather, partners in clinical research (2, 3). In the hours and days that followed, Francis Collins, director of the U.S. National Institutes of Health (NIH), reiterated this view, using words such as “participants” and “partner” when referring to people involved in clinical research (4). As a veteran citizen scientist and patient advocate (4), I was moved to tears to hear such proclamations from people other than my passionate fellow advocates. However, PCORnet’s efforts and PMI’s endeavor to enroll a million people—called All of US—will spur the advancements we see each only if we, the people, take advantage of these unprecedented opportunities and act with boldness to overcome myriad misaligned incentives, business interests, and general inertia against change.

BUILDING THE WE: TRUE PARTICIPATION
Thousands of individuals affected by common and rare

the investigators and not by all stakeholders. Participants want not only to be invited to the table but also to design and lead the meal with other stakeholders. There is a great deal of “us and them” language in biomedical research. Investigators point to “those patients,” and activists complain about “those investigators.” Clinicians are often left out of the process completely. When these roles are considered dichotomous and separate instead of part of a continuum, it is difficult to create authentic partnerships.

Participants have a place throughout the research continuum, including the proposal and prioritization of research questions, study design, engagement of study participants and their recruitment and retention, conduct of research and data analysis, and implementation and dissemination of results and, often, individuals’ own data. However, if we intend to engage a large and diverse array of people in clinical research, participation has to be made as frictionless as possible by creating mechanisms in communities where people live, work, and play, with community representatives leading the way. In addition, the research conducted must have relevance to the engaged parties by addressing questions that arise from communities of participants. If a study is built on the needs of individuals, families, and communities, then the results of research must be transparent and tangible—traits that run counter to the current culture. Researchers often do not return even the published results to the participants, let alone a lay summary or other accessible communication. If an effective intervention results from a clinical study, the process can take more than 10 years for the new intervention to be integrated into clinical practice (5). The new U.S. national efforts, particularly



Sharon F. Terry, President and CEO of Genetic Alliance, Washington, DC, 20008, USA, and serves as a member of the PCORnet leadership and the Patient Advisory Panel of the U.S. Precision Medicine Initiative. Email: sherry@geneticalliance.org



People not data

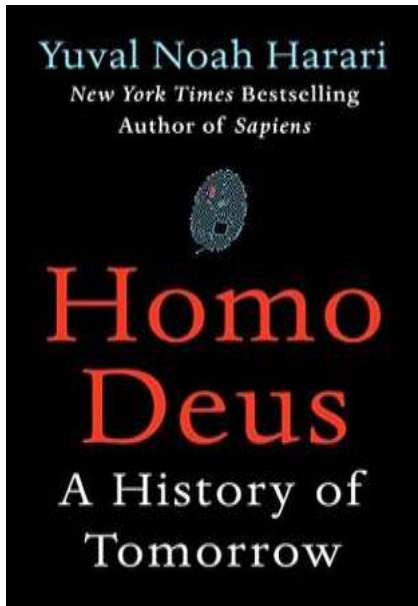
“He who studies medicine without books sails an uncharted sea, but he who studies medicine without patients does not go to sea at all.”

William Osler

“It’s important to remember that behind every data point is a daughter, a mother, a sister – a person with hopes and dreams.”

Melinda Gates





- “In the early twenty-first century the train of progress is again pulling out of the station – and this will probably be the last train ever to leave the station called Homo sapiens. Those who miss this train will never get a second chance. In order to get a seat on it you need to understand twenty-first-century technology, and in particular the powers of biotechnology and computer algorithms.”